

RESEARCH ARTICLE

Improving management of psoriasis patients receiving biological treatment: A qualitative approach

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Abstract

Aim: To investigate psoriasis patients' and healthcare professionals' experiences and perspectives of follow-up consultations.

Design: A qualitative study with a phenomenological-hermeneutic approach.

Method: Participant observations of consultations and semi-structured interviews were conducted with patients receiving biological treatment, together with two focus groups with healthcare professionals, from June 2018–January 2019. Data were analysed using a qualitative structured approach based on Paul Ricoeur's philosophy of interpretation.

Results: Consultations had a strong biomedical and corrective approach focusing on lifestyle behaviour change, measurements and permanent routines. Healthcare professionals felt the need for enhanced competencies providing lifestyle behaviour change support and the possibility of providing patients more specific strategies. They were faced with a dilemma between lacking the right skills and having a professional duty. The frequent follow-up visits did not fit in with the patients' everyday lives.

KEYWORDS

biological treatment, participatory design, psoriasis, qualitative research

1 | INTRODUCTION

This paper presents the findings of an explorative qualitative study and is part of a larger participatory design study on how to improve the management of patients with psoriasis receiving biological treatment. A participatory design study consists in health care of three phases. Phase one is identification of needs through exploration of experiences and obtaining knowledge about the current clinical practice. Phase two is the design of a telemedicine solution, to meet the needs identified in phase one. In phase three, the telemedicine solution is tested in clinical

practice (Clemensen et al., 2016). This paper reports findings from phase one as part of the identification of needs, to gain an in-depth understanding and improve the management of this patient group based on the patients' and healthcare professionals' (HCPs') experiences.

2 | BACKGROUND

Psoriasis is a complex, chronic, lifelong inflammatory skin disease characterized by local or widespread, thick, white, scaly, pruritic

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plaques. Psoriasis is also associated with various comorbidities, including arthritis, depression and cardiovascular disease (Dalgard et al., 2015; Puig, 2017). Psoriasis affects approximately 2%–4% of the population in Western countries (Parisi et al., 2013). The economic burden of the chronic disease increases with disease severity (Jungen et al., 2017), with psoriasis comorbidities contributing to the costs (Brezinski et al., 2015; Feldman et al., 2017).

Comorbidities—such as psychological distress, depression and anxiety and cardiovascular diseases—contribute to the impact on patients' lives (Griffiths et al., 2018). Recognizing and managing psoriasis as a long-term complex chronic disease, including addressing patients' psychological distress, is requested by patients (Nelson et al., 2013) but can be challenging to achieve in clinical practice (Khoury et al., 2017). The use of biological treatment has improved the health outcome for patients with moderate to severe psoriasis, by reducing physical symptoms, psychological distress and depression (Salame et al., 2019). Biologics are drugs that target specific parts of the immune system and are for the indication of patients with moderate to severe psoriasis (Rønholt & Iversen, 2017).

In Denmark, patients receiving biological treatment have quarterly follow-ups, which can be a burden on themselves and not all patients are satisfied with their treatment as they are concerned about lack of effect and side effects (Tveit et al., 2019). However, patients are reluctant to discuss such concerns because they fear discontinuance of their biological treatment (Trettin et al., 2020). The transition from having psoriasis to having clear skin can be a major physical change but some psychological issues caused by psoriasis may remain untreated affecting patients self-images (Trettin et al., 2020). Thus, changes in patients' illness perceptions are for some patients a significant challenge in spite of the physical improvement of the skin. Furthermore, there are distinct differences in the perceived severity of psoriasis among patients and HCPs (Lebwohl et al., 2014) which may create obstacles during consultations, resulting in divergent treatment goals that complicate a patient-centred approach (Strohal et al., 2015).

Consequently, there might be several challenges in the follow-up consultations for patients with psoriasis receiving biological treatment, suggesting that there is a potential to improve the management of this patient group.

2.1 | Research question

What are patients' and healthcare professionals' experience and perceptions of the follow-up consultations and current clinical practice?

2.2 | Design and method

This study employed participant observation, individual interviews and focus group interviews to obtain a deeper understanding of clinical practice and to investigate patients' and healthcare professionals'

TABLE 1 Participants' characteristics—semi-structured interviews

Variable	Value
Median (range) age (years)	45 (23–70)
Sex	
Male	8
Female	7
Employment status	
Employed	9
Retired	5
Not working	1
Relationship	
Single	7
With partner	7
Widowed	1
Treatment	
Ustekinumab	7
Etanercept	2
Adalimumab	3
Secukinumab	2
Infliximab	1
Median treatment years	4 (0.5–16)
Psoriatic arthritis	6

experiences of and perspectives on the follow-up consultations they attend every three months. Combining these qualitative methods resulted in rich descriptions that created a comprehensive understanding. A phenomenological-hermeneutic approach was adopted, inspired by Ricoeur's thoughts about narrative and interpretation (Ricoeur, 1976). To ensure and improve the transparency of this study, the consolidated criteria for reporting qualitative research checklist guided the reporting of this study (Tong et al., 2007).

2.3 | Setting

The study was carried out in an outpatient clinic at a university hospital in Denmark, where patients receiving biological treatment have regular follow-ups every three months. Treatment with biologics is associated with higher treatment cost compared with traditional treatment options (Ahn et al., 2013). In Denmark, the costs of biological drugs are covered by the health system. Patients were included using a purposive sampling strategy, to achieve diversity in sex, age and geographical distance. All participants were over the age of 18 and were Danish speaking (Table 1).

2.4 | Sampling and recruitment

All patients scheduled for a follow-up visit received written information that the first author would be present at the consultations

and gave their consent. In total, 49 patients were observed. During the observation, the first author recruited patients for face-to-face interviews, using a purposive sampling strategy to create a diverse demographic group. In total, 18 participants signed an informed consent and were contacted by phone to schedule the interview. Two did not respond and one declined to participate due to a busy work schedule. Thus, 15 patients participated (Table 1). HCPs were contacted by email and invited to one of two focus group interviews. Those invited were experienced clinicians, both medical doctors and nurses, involved in the care and management of psoriasis patients receiving biological treatment. In total, 13 HCPs were invited and 10 participated in the focus groups (Table 2). Two declined due to busy work schedules and one due to sickness.

2.5 | Data collection

Participant observations were conducted from June–September 2018 and followed an observational guide developed and based on Spradley's nine dimensions (Spradley, 2016). The aim of participant observation was to observe and understand the clinical situation by grasping insiders' (patients' and HCPs') points of view, to obtain a deeper understanding and more insightful description of the current practice (Bundgaard et al., 2011). After each observation, the descriptive field notes were transcribed.

The first author conducted the individual interviews from September–November 2018 at the location preferred by the patients: either in the patient's home ($N = 9$), at the hospital in an undisturbed room ($N = 4$) or by telephone ($N = 2$). Interviews were digitally recorded and transcribed verbatim. An interview guide was developed based on existing scientific knowledge and the preliminary

findings from the participant observations. No further patients were recruited since the interviews reached data saturation meaning that no new information was obtained in the last three interviews.

The two focus group interviews, conducted in January 2019, each included both nurses and physicians, with the intention of maximizing the exploration of their various perspectives (Kitzinger, 1994). An external observer was present during the interviews to take notes and ask questions to clarify issues raised if necessary. During the focus groups, the participants were asked to discuss their experiences of the current practice related to managing psoriasis patients, how they thought patients perceived the current practice and to discuss suggestions for a future management. Then, the participants were presented with findings from the participant observations and individual interviews and asked to discuss them. All interviews were digitally recorded and transcribed verbatim.

2.6 | Data analysis

All transcriptions and field notes were gathered as one text and analysed using Ricoeur's theory of narrative and interpretation (Pedersen, 1999; Ricoeur, 1976). This was a dialectical movement between three levels: a naïve reading, structural analysis and critical interpretation and discussion. The text was read several times to obtain an initial impression of what the text was about. This initial analysis was written down. Then, the text was analysed in a more structured manner and the interpretation identified units of meaning (what is said) and units of significance (what the text speaks about). Three main themes emerged during the ongoing movement backwards and forwards in the dialectical process. In the critical interpretation and discussion, the themes were further interpreted and discussed with existing research and relevant theory (Pedersen, 1999).

2.7 | Ethics

The study was approved by the Danish Data Protection Agency (2012-58-0018), following the principles of the Declaration of Helsinki (World Medical Association, 2013). According to Danish law, approval from the National Committee on Health Research Ethics is not required.

3 | RESULTS

The naïve reading revealed that the follow-up consultations had a biomedical focus and that documentation and routine practices seemed to be prominent. It became apparent that patients had a sense of security about being monitored, but questioned the need for frequent follow-up visits. In the structural analysis, three themes emerged: "Consultations framed in a biomedical context," "The ambivalence of providing lifestyle behaviour support" and "Balancing everyday life and treatment." Consultations referred to in the results

TABLE 2 Focus group HCP participants' characteristics

Variable	Value
Focus group 1	
Sex	
Male	1
Female	4
Occupation	
Medical doctor	2
Nurse	3
Experience with psoriasis patients	5,8 (2–10)
Focus group 2	
Sex	
Male	0
Female	5
Occupation	
Medical doctor	2
Nurse	3
Experience with psoriasis patients	6,6 (2–11)

sections are all follow-up consultations for patients with psoriasis receiving biological treatment.

3.1 | Consultations framed in a biomedical context

Consultations were structured in a way that meant that every patient went through the same routines and measurements. Patients' experiences related to psoriasis, life in general or specific questions asked were not always answered:

Doctor: "How's it going?" Patient: "More or less as usual, but my nails are getting worse and worse."
 Doctor: "You don't have psoriatic arthritis?" Patient: "No."
 Doctor: "Do you have high blood pressure?" Patient: "I'm taking measurements at home."
 Doctor: "You haven't had blood tests?" Patient: "I tried but gave up because of the waiting time."
 Doctor: "Do you have any side effects?" Patient: "No."
 Doctor: "Can I take a look where there is something to see?"
 The patient shows the doctor the areas on the left hip, forearm and knee and says: "These are the permanent marks."
 The doctor looks briefly at the patient and says: "Do you smoke?" Patient: "Thirty years ago."
 Doctor: "How much?" Patient: "Less than 10."
 The doctor has the PASI calculator page open on the screen and keys in something on it and in Dermbio [database].
 The patient says: "There is a little on the scalp."
 The doctor does not respond, but asks more about smoking and puts a mark next to some things on the screen.
 Doctor: "The most important thing is that you have new blood tests so you can get your medicine." (field note)

The HCPs were subject to strict rules on documentation and routines that were familiar to both them and the patients. Routines took a systemic and instrumental approach and the need to document measurements outweighed the patients' needs and requests. The HCPs were well acquainted with the demands of the system at the expense of an individual attention to the patients, which lead to frustrations:

I think it's a little bit hectic. Because I have to click a lot of things, both in Dermbio and in the medical record. I just think that, from the patient coming in the door, sitting and banging away and typing and typing and sliding around between Dermbio and Cosmic [electronic patient record] and typing and of course talking a little with the patient. It would really relieve me of some of the work if some of it [data entry] took place on an iPad in the waiting room or in a different room where the patients could fill everything out themselves [weight, smoking habits, DLQI]. Then the patient could enter the consultation and we could just

sit and talk on the basis of what they have filled out. That, I think would restore calm.

(focus group 2, doctor)

A type of work assembly line was prominent, and HCPs felt constrained by the requirements to document. There was a wish to improve interactions and conversations with patients and there seemed to be a need for deviations from the routine, to create a more focused consultation. The close monitoring of the disease created feelings among patients of security and being in good hands. Nevertheless, the way consultations were performed could have a negative impact on patients' experiences:

It can be a little distressing. I find it very, very difficult that people such as doctors or nurses don't look me in the eye or aren't accommodating and I have experienced that; I mean, it annoys me.

(13, female patient)

Participants were unsatisfied and disappointed with consultations when HCPs were not fully present or attentive and focused more on documentation and the computer screen, instead of developing and maintaining relationships, where they would receive the patient as a person with individual needs. Thus, both patients and HCPs experienced the number of consultations to be excessive.

3.2 | The ambivalence of providing lifestyle behaviour support

All consultations contained aspects of lifestyle behaviour support, vital measurements and reporting of alcohol and tobacco use. In some cases, the reason for this was not explained:

Doctor: "I see your weight is a little too high, it might be a good idea to get some exercise, maybe ride a bike, or go for a walk with the dog, if you have one".
 Patient: "It's not like I'm not doing anything, I play both badminton and.. it's probably more diet", while looking down.
 Doctor: "Yes, diet is also important", while looking at the screen and typing.
 Patient: "This has probably changed a lot, coming here, now it's a lot about living healthily", while looking around at us all.
 Nurse: "Yes, that's right".
 Doctor: "Do you need some prescriptions?" (field note)

Lifestyle behaviour support was often given as general advice; however, to some patients, the connection between psoriasis, lifestyle and risk of developing comorbidities, was not apparent. Patients were unable to adapt their expectations in relation to the agenda of the consultation and could not prepare themselves ahead of a consultation. Frustrations occurred when patients did not want to discuss their lifestyle:

But every time you see a doctor. I'm a smoker, just try to listen, let me be. And it really is a drag, because you know it well yourself. If the doctors out there knew my whole life story, it might be that they would think, you know what Karin (fictional name), you have really done very well, that you are where you are today and if they could just stop pressing me

(2, female patient)

Addressing lifestyle, for some, was experienced as castigation and resulted in feelings of discomfort and irritation and a sense that their right to self-determination was being challenged. Going through the same lifestyle checklist at every visit without exploring the individual patients' perspective and needs or everyday life, meant that changes in lifestyle that could have benefitted the patient never happened. HCPs likewise had concerns regarding providing proper lifestyle behaviour support:

We don't deal with the actual sore point; just that patients have a better lifestyle in general. We give them medicines costing 200,000 DKK, but we don't help them where they really need help, with diet and exercise and no cigarettes; there are no initiatives. We can say to them try to lose weight, try to stop smoking and so on, but in reality, we have nothing to offer them. I think that is a failure of care; we can give a shot in the thigh, but all those difficult things – we can't deal with them

(focus group 2, doctor)

To the HCPs, there was a need for enhanced competencies in providing lifestyle behaviour support and the being able to provide patients more individual strategies. This led to feelings of inadequacy and insecurity among HCPs about their approach and to questioning whether they actually helped patients with an improved lifestyle. At the same time, they felt obligated to inform patients about physical comorbidities—by virtue of their profession. As a result, there was a dilemma between lacking the right skills and having a professional obligation. HCPs recognized that the consultations did not match the individual needs of patients, indicating that the format of consultations needed to change.

3.3 | Balancing everyday life with psoriasis and treatment

A biomedical focus at the consultations resulted in missed opportunities regarding patients' specific needs. The following quotation is from a dialogue between a patient in his early 30s who is telling the HCPs about his fingers feeling stiff and hurting. The patient shares that he feels stressed and has an 11-month-old baby and a pregnant wife at home:

Doctor: "The task at home is to lose weight." Patient: "That I know very well! Everyday life is pressured."

Doctor: "Yes, I really understand that, it is just easier to create good habits now, when you are young."

Patient: "Yes, definitely", answers and looks away; he turns his wedding ring. He shows his fingers to the doctor again. Doctor: "Yes, I'm not an expert in this."

Patient: "Neither am I." (field note)

The agenda of the consultations did not always match the expectations of patients, because it did not necessarily include how patients perceived their well-being in everyday life. When patients expressed their needs or showed signs of vulnerability, HCPs often missed opportunities to address or discuss these with the patients. Missing opportunities to discuss important issues had a significant impact on patients' everyday lives and created tensions. The routines and focus on documentation seemed to overshadow the challenges patients experienced in everyday life. Although patients expressed satisfaction regarding their treatment, they questioned the frequency of their visits. Stable patients with no perceived lifestyle issues were frustrated by the quarterly mandatory check-ups. Having to fit them all in while maintaining a job and balancing family life had an impact on patients' everyday lives:

Patient: "Is it not possible to increase the amount of medication (to take home), so that I don't have to come every 3 months? I've had the medicine since 2012 and I put the whole machinery into operation every 12 weeks, I don't need that, I've been stable since 2012."

Nurse: "Unfortunately not as it [Department policy] is right now." (field note)

Another patient said:

It is really something that just has to be done and if I am completely honest, I only come because I need to collect my medicine; otherwise I would not come, I think it is a waste of time. (field note)

HCPs recognized this, as they experienced that the frequent visits for some patients were more a necessary evil:

They don't need to sit and talk. They just want to get in and out quickly. They just want their medicine.

(focus group 2, nurse)

Check-ups that were perceived as unnecessary created impatience among patients, which was well known among the HCPs. Nevertheless, because of the national guidelines, they had to follow the same routines and measurements and could not adapt the care to suit the actual needs and daily plans of the patients. Thus, both patients and HCPs seemed to be trapped by the routines.

4 | DISCUSSION

Follow-up consultations for biological treatment of psoriasis adhere to a checklist focusing on efficacy of the treatment and adverse effects and a corrective approach focusing on lifestyle behaviour change, vital measurements, documenting and entering data into databases. HCPs feel they need training in lifestyle behaviour change support and to be able to provide individual care. Patients feel safe being monitored; however, they also request an individual and personal approach, highlighting the importance of communication and the relationship between them and the HCPs. The frequent follow-up visits, without much focus on what was important for the patient, did not fit in with the patients' everyday lives.

Contrary to previous research, which has demonstrated how lifestyle behaviour change support not was mentioned during consultations (Nelson et al., 2013) (Nelson et al., 2014), our findings indicate that this has changed. Even though this support is not included, it may be that ways of providing lifestyle behaviour support could be improved. Lifestyle behaviour change was addressed by going through a checklist, without going into the individual patient's needs and the relevance of the change to everyday life. In the current study, we found that clinicians lack the confidence and skills to address lifestyle behaviour change and are in need of training (Nelson, Barker, et al., 2013; Nelson et al., 2014). HCPs felt inadequate, because they did not feel capable of providing patients with specific strategies. They recognized that the notion of changing health behaviour by way of simply providing generic information and advice may not result in any advantageous lifestyle behaviour change. A starting point to improving HCPs' knowledge and skills to manage psoriasis could be the Psoriasis and Wellbeing (PsoWell) training programme (Chisholm et al., 2017), which takes a theory and evidence-based approach. PsoWell was conducted in eight locations in the UK in 2019 and was well received by participants but has not been implemented in the curriculum of dermatologists. Little is known about its effect on patient outcome. Even providing personalized risk information does not necessarily have a strong or consistent effect on health-related behaviour (French et al., 2017), emphasizing the need to find new interventions that facilitate behaviour change (Keyworth et al., 2018). A theory-based approach, involving tools, techniques and frameworks, has the potential to result in behaviour change, but is not commonly used outside the research context (McSharry et al., 2020). However, the NICE guidance recommendations on changing health behaviour recommend training, to ensure that HCPs have the required skills and knowledge to assess behaviours and individual needs and that those skills are based on relevant theories (National Institute for Health and Care Excellence, 2007). In addition, the NICE guidance recommends that the intervention matches the patient's needs, including the physical and psychological capability to make a change. Patients experienced the current forms of lifestyle behaviour support as admonishing, leaving them with feelings of loss of free will, which, according to self-determination theory, undermines intrinsic motivation, self-regulation and well-being (Ryan & Deci, 2000). Consultations on improving lifestyle should support

autonomy, giving a sense of volition in reaching a common goal. This is in contrast to our finding, where some of the patients experienced the lifestyle behaviour change support as admonishing and left them with feelings of discomfort and irritation, which challenged their right to self-determination.

According to Bourdieu, *doxa* refers to the tacit knowledge or beliefs that characterize a field, being so obvious and natural that they are not discussed nor made explicit (Bourdieu, 1990). The concept of *doxa* could be used to denote a doctrine or unspoken rule that underlies the routines and decisions made in clinical practice. The current study found that HCPs were subject to strict rules around documentation and routines that were familiar to both them and the patients. We also found that the HCPs were well acquainted with the demands of the system at the expense of an individual attention to the patients, which could be explained by the *doxa* of consultation. Thereby, when HCPs take a biomedical approach, it is not necessarily a conscious choice. Integrating Bourdieu's theory may help to explain and understand why consultations play out the way they do and why routines and interaction may prove challenging to change, despite the fact that it was requested by both patients and HCPs. In addition, Bourdieu's theory provides an understanding of current practice and emphasizes the need not only to suggest new or different ways of communicating with patients, but to take into account the importance of understanding the social structure in clinical practice and the communication between patients and HCPs. Communication is important to patients and is often referred to by patients as one of the most important aspects of their treatment and management, adherence, or to care in general (Zschocke et al., 2017). Strengthening the communication and relationship between HCPs and patients is an ongoing issue that can always be improved. Our findings indicate that there is a need for the development of a new approach in clinical practice, under consideration of the fact that practice is not easily changed.

Not all the participants in our current study felt the need to attend quarterly consultations. Providing a setup that would allow HCPs to document and keep notes in compliance with the guidelines without taking time from the consultations would be beneficial. This would mean that consultations could be more focused and individually needs-based. Some patients need regular follow-up visits, while others do not. Reducing the number of consultations, changing their focus and allowing tele-consultations may be some options. These solutions could be used in the care of patients with emergent or chronic skin diseases (Ebner et al., 2008; Massone et al., 2005; Schreier et al., 2008). Furthermore, the solutions are accepted by both patients and healthcare workers (Fruhauf et al., 2012), although it has been suggested that new technological services should be closely adapted to patients' (Greis et al., 2018). A tele-medical solution could be a promising and reliable tool for the long-term management of patients with psoriasis on systemic treatment (eg biologics) (Koller et al., 2011). In this regard, it would be relevant to design and develop a technological solution that could complement in-person check-ups, but also allowing patients to prepare ahead of consultations. This would allow them

to contribute to the agenda and to self-monitor, thus empowering patients and facilitating a patient-centred care approach.

4.1 | Strengths and limitations

A limitation of our study is that data were collected at one outpatient clinic only, which may question the transferability of the findings. However, the outpatient clinic receives patients from all over the Region of Southern Denmark and the qualitative approach provided rich, unique descriptions of how patients and HCPs experience the consultations. Furthermore, the results provided new knowledge on how to improve the management of patients with psoriasis receiving biological treatment. Another limitation is that the presence of the first author during the observations may have influenced the behaviour of the participants. In qualitative research, the researcher always affects the phenomenon that is under investigation (Kirsti Malterud, 2001). Nevertheless, because participants were recruited for the semi-structured interviews shortly after their consultations, the person doing the recruitment was already familiar to the patient. Furthermore, combining various qualitative methods and the use of researcher triangulation enhanced the validity of the study (K. Malterud, 2001). The first author has a background as a HCP and was employed at the institution where the data were gathered. However, she was not involved in the care of patients and could therefore attend the participant observation in an open-minded way. To avoid re-producing our preconceptions, reflexive practice was performed among the authors, including the assessment of subjectivity, throughout the entire study. The data analysis process was conducted systematically to ensure the quality and to eliminate misinterpretation or over interpretation.

5 | CONCLUSION

This study provides insight into consultations with psoriasis patients receiving biological treatment and how these patients and HCPs experience them. Some patients experienced lifestyle behaviour change support as admonishing. HCPs experienced ambivalence, and they felt obligated to provide the support, but experienced a need to enhance their competencies so that the patient would benefit. The biomedical agenda and focus on lifestyle behaviour change created a work assembly line and patients and HCPs experienced the number of consultations to be excessive. They seemed to be trapped in the consultation routine, even though both parties wanted a change. Thus, our findings emphasize the need of a new approach in clinical practice to facilitate the patients' perspectives and needs into the communication between HCPs and patients.

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CONFLICT OF INTEREST

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AUTHOR CONTRIBUTIONS

The funders had no role in study design, data collection and analysis, decision to publish or preparation of the manuscript.

DATA AVAILABILITY STATEMENT

This study reports qualitative data collected from researchers and stakeholders. The nature of qualitative data means that it is difficult to fully anonymize. Participants were not asked to agree to their data being available. Only the researchers had access to the stored data.

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